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ABSTRACT

This paper discusses cyclical grieving, which is described as an intermittent reoccurrence of one or more emotions that are part of the grieving process experienced by parents who have children with disabilities. A study to support the concept of cyclical grieving used a naturalistic approach with face-to-face interviews to explore ten parents' retrospective perceptions of their experiences in rearing a child with a disability. Results of the interviews found the parents vividly remembered how they felt when they were told that their child had a disability. The emotions they felt included: disappointment; sadness or depression; loneliness; fear; anger; frustration; shock; devastation; numbness; unsureness; and feeling trapped and sorry for the child. Both mothers and fathers reported having these or similar emotions reoccur intermittently during the life span of their child. Events that triggered grieving included: health or behavior issues; developmental milestones or age appropriate expectations; family issues and relationships; aged parents and retirement concerns; unusual caretaking demands; professional and programmatic issues, society's lack of understanding and sensitivity; and seemingly insignificant events. (Contains a Cyclical Grieving Model, and 29 references.) (CR)

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Cyclical Grieving: Reocurring Emotions Experienced by Parents Who Have Children with Disabilities

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Cyclical Grieving:
Reocurring Emotions Experienced by Parents who have Children with Disabilities

The Grieving Process

Grieving is a natural human response to a significant loss. The loss might be that of a loved one, a job, a marriage or a dream. Grieving is not just the sadness that is associated with mourning, but is a range of emotions that humans experience as they try to accept the loss, change, death, or disappointment which has happened in their lives (Wurzbach, Lesniak, & Wilson, 1988). Grieving starts spontaneously and doesn't appear to require any learning period (Moses, 1983). The emotions experienced during grief seem to be intrinsic and cross-cultural (Lewis & Rosenblum, 1974) and are part of the natural healing process (Schneider, 1983).

Kubler-Ross (1969) first identified a consistent pattern of emotional responses in her work with terminally ill patients and referred to this pattern as the stages of grieving. The stages Kubler-Ross identified were denial, anger, bargaining, depression and acceptance. This pattern of grieving has been referred to as the stage model because of the belief that a person experiencing grief works through each of these five stages ending in acceptance.

Parents who have a child with a disability and have lost the child they have dreamed and fantasized about throughout their pregnancy also grieve (Cameron at al., 1992; Childs, 1985; Drotar, Baskiewicz, Irvin, Kennell & Klaus, 1975; Fraley, 1990; McCollum, 1984; Moses, 1983; Quine & Pahl, 1987; Solnit & Stark, 1961). According to Moses (1983), the grief process begins when an initial diagnosis is received by a parent. One father explained, "After we found out our first born was permanently brain damaged and severely/profoundly retarded I was devastated" (May, 1991, p. 8).

The stage model of grieving has been used to describe the grieving process these parents experience. However, parents have indicated that working through a series of stages and reaching a final stage of acceptance does not accurately describe their pattern of grieving and challenge the accuracy of this model for their type of loss (Allen & Affieck, 1985; Cameron at al., 1992; Featherstone, 1980; Olshansky, 1962; Schneider, 1983).

Olshansky (1962) used the term chronic sorrow to describe the psychological reactions of parents who have children with mental retardation. He further described this sorrow as the unending feelings of grief which are a natural rather than pathologic reactions to loss. Olshansky identified other factors that might also influence the intensity of the sorrow such as the parents' personalities, ethnic group, religion, and social class. He contended that the intensity of the chronic sorrow changed over time, but was present throughout the life of the child. Parents have reported that the feelings of grief do disappear for short or prolonged periods of time. Therefore, the theory of chronic sorrow is challenged as an accurate description of the grieving process experienced by these parents.

Moses (1983) supported the premise that parents of children with disabilities experience grief as they grieve the loss of their dream child. He stressed that it is the grieving process which allows parents to separate from their significant lost dream (Moses, 1977). Moses (1983) pointed out that the emotions, which he called feeling states, have no specific order; one is not a prerequisite for another, and the feelings can be felt simultaneously. He also indicated that the feelings can return and be re-experienced. He stressed that successful grieving is contingent upon significant human interactions and that "one cannot grieve alone" (p. 14). Moses pointed out that each feeling serves a specific function which helps the parent separate from the shattered dream. And, once the parents separate, they are able to dream new dreams.

In two recent studies, attempts were made to determine if the grieving process for parents with children with disabilities ends in a final stage of acceptance or if it continues as chronic sorrow as suggested by Olshansky (1962). In 1984, Blacher conducted a review and critique of the literature regarding the stages of adjustment experienced by parents who have children with disabilities. According to her findings, a number of researchers who conducted studies in the 1970's believed that parents did reach a stage of acceptance. However, in 1981 Featherstone supported Olshansky (1962) by suggesting that parents may never reach a final stage of acceptance. Blacher and Featherstone felt that most stage theories oversimplified what was actually happening to parents. It is important to note that many of these earlier studies relied on inferences made as a result of clinical practices. Empirical research which examined parents and their reactions over time had not been conducted.

In 1992, Cameron et al. conducted a descriptive study interviewing 63 mothers with children with developmental disabilities to examine their emotional

experiences. The researchers used a retrospective approach in order to explore the mothers' emotions over time. The results of this study indicated that rearing a child with a disability produces profound emotional experiences for the mother. The mothers recalled having experienced the emotions of grief when they learned of their child's diagnosis and indicated that these emotions emerged and re-emerged as the child grew older. These findings support those of Featherstone (1980) and Olshansky (1962).

Cyclical Grieving

While other authors have written about the grieving process, this researcher has taken this information one step further and developed a visual representation of cyclical grieving which will help parents and professionals more fully understand the cyclical nature of grieving as it relates to parents who have children with disabilities. Cyclical Grieving is based on the sources of grief already discussed and from hundreds of parents with whom the author has worked during the past twenty years.

Cyclical grieving (Blaska, 1994) is the intermittent reoccurrence of one or more emotions which are part of the grieving process and experienced by parents who have children with disabilities. Cyclical grieving occurs throughout the life cycle of the family, however, the duration and intensity of the reoccurring feelings diminish with the passage of time. During the days, weeks, and months when grieving is not occurring, parents have reported being free of the intense emotions.

The occurrence of cyclical grieving does not preclude parents from deriving joy from their child's development and achievements. When a parent who participated in this study and whose child has mild retardation was asked what was most rewarding about her daughter, she responded, "The love she gives us. She has one foot in the adult world and the other in childhood so she looks at life in a joyful way...my other children are better people because of all of this too." Many parents have reported while being a parent of a child with developmental disabilities is challenging, it has made them stronger (Wikler, Wasow, & Hatfield, 1983).

Cyclical Grieving

(Insert Figure 1 about here)

Cyclical Grieving (Blaska, 1994) represents the cyclical nature of grieving experienced by parents who have children with disabilities (see Figure 1). The visual representation is illustrated with three concentric circles which represent the following:

Inner Circle:

The inner cycle represents the shattered dream parents experience when they find out their child has a disability. When parents are expecting a baby, they dream about what the child will look like, their hopes for the child's talents and capabilities and the child's future life. When the child is born with a disability or when the disability is identified later in the child's life, these dreams are shattered and no longer possible. According to Moses (1983), the severe loss experienced by these parents is the loss of their dream child. Parents grieve for their dream child; this grieving helps the parents let go of their dream which allows them to refocus and dream new dreams for their child.

Second Circle:

The emotions depicted in the second circle are feelings parents have reported experiencing at the time of diagnosis and intermittently thereafter. The emotions included in this model are a representation of feelings that parents have reported; however the listing is not exhaustive (Blacher, 1984; Cameron et al., 1992; Fraley, 1990; Moses, 1983). The words are placed randomly within the circle to illustrate that the emotions are not experienced in any predetermined order. The emotions may appear and reappear with a parent experiencing one, two or more simultaneously (Cameron et al., 1992; Childs, 1985; Moses, 1983).

Outer Circle:

The third or outer circle depicts four of the life cycles of a family, namely, family with young children, family with adolescents, family launching children, and family in later life (McGoldrick & Carter, 1982). The exact number of life cycles is somewhat arbitrary with theorists having identified as many as 24 and as few as six (Carter & McGoldrick, 1980). This model concentrates on four major life cycles during which time the child with the disability comes into the family system causing the family to adapt and cope with the child's unique needs which then continues throughout the life of the child. The family life cycle is one dimension of a family systems framework and views a family as it changes and

moves through time. The change alters the family structure and its functioning priorities which in turn change the way the family interacts. The challenge for a family who has a child with a disability is that while they cope with the changes in the family system, they also have to deal with the chronicity of their child's disability (Turnbull, Summers, & Brotherson, 1986).

The dotted arrows away from and toward the emotions as well as away from and toward the developmental stages of the family life cycle represent the cyclical nature of grieving. Parents move toward the reoccurrence of the emotions, and further away, with this movement contingent on events in their lives.

During the life cycle of a family, a number of events trigger the reoccurrence of one or more of the emotions that make up the grieving process. Parents in this study and others have acknowledged the cyclical nature of their grieving (Cameron et al., 1992; Moses, 1983; Olshansky, 1962; Wikler, Wasow, & Hatfield, 1981). "Even those who can tolerate their grief and depression proceed with the work of mourning slowly and unevenly to protect themselves from being overwhelmed, and to preserve their capacity to function in daily life" (McCollum, 1984). Another comment from a parent describes the cyclical nature. "Perhaps disappointing would be a better word than sorrow. I firmly believe we did have many peaks and valleys. There is sadness, but many joyous and funny moments too" (Wikler, et al., 1981, p. 69).

Cyclical Grieving: An Exploratory Study

To support the concept of Cyclical Grieving, an exploratory study utilizing a naturalistic approach with face-to-face interviews was conducted to explore parents' retrospective perceptions of their experiences in rearing a child with a disability. One of the primary data sources in naturalistic inquiry is the interview because it elicits information that isn't available from observation and questionnaires (Odom & Shuster, 1986). Data collected through the interview process help us to understand the perspectives and experiences of the parents being interviewed (Fetterman, 1989; Patton, 1987). A master level student with a background in social work was trained as a research assistant and conducted the interviews, transcribed the interview notes, and participated in the data analysis. The major purpose of this study was to determine if parents of children with disabilities experience cyclical grieving. Research questions to be addressed were: 1) What emotions did parents experience when their child's disability was

first diagnosed, 2) Did any of these emotions reoccur during the years of rearing their child, 3) What events triggered the emotions to reoccur, and 4) Were there any similarities or differences between mothers and fathers and the emotions they experienced?

Participants

Local support groups and special education professionals were contacted with a request for volunteer parents to participate in this study. The sample was not random and was obtained by convenience. All of the parents were Caucasian, were 49 to 68 years of age, lived in rural areas, were of lower and middle socioeconomic status and had children with disabilities who ranged in age from 21 to 39 years. Seven two-parent families volunteered for the study; however, only three fathers agreed to participate (N=10 [7 families]). Interviews were conducted with 7 mothers and 3 fathers. A range of disabilities was represented (i.e. Down syndrome, blindness, autism, cerebral palsy, mental retardation) with the severity of the disabilities ranging from mild to severe. The children referred to in this study are adults with four living at home and the others in group homes or supervised apartments. Currently two are employed in sheltered workshops and three in supported employment.

Procedures

Prior to the beginning of this study, the research assistant conducted a pilot study to ensure clarity of questions, sequence of questions and levels of probing. She then interviewed seven mothers and three fathers in their homes using a structured interview format that consisted of nine questions. All participants were asked the same questions in sequence. Questions were open-ended to elicit the parents' perceptions of their emotional experiences in rearing a child with a disability. The questions, prompts and cues were stated in a neutral manner to eliminate any possibility of influencing the parent's response. The questions focused primarily on the thoughts, feelings and reactions the parents experienced in relation to their child's diagnosis and subsequent emotional reactions to events in their lives. Parents were asked to think about their lives with their children and indicate if any of the emotions of grief which they had identified had reoccurred. It was recognized that parents may have difficulty recalling specific events because of the years that had passed (i.e. 21 to 32 years). To help parents focus on past events, the interviewer first asked the

parent to consider the first five years of their child's life, then to focus on the elementary years, adolescence, high school, and post high school. Focusing on a specific time-span helped the parents recall events that were significant to them. Probes and cues were also used to elicit responses.

When both parents volunteered for the study, interviews were conducted separately, one following the next to eliminate any opportunity for discussion. The intent was to tape record the interviews. However, the majority of parents were uncomfortable with this procedure. Subsequently, notes were taken during the interviews and shared at the conclusion of the interview. To increase accuracy and reliability, the interviewer transcribed all notes within 48 hours of each interview. Follow-up call were made to three participants to clarify data.

Results

While this was an exploratory study with a small sample, the results do support the accuracy of the concept of Cyclical Grieving in describing parents' emotional experiences as they rear their children with disabilities. All of the parents interviewed vividly remembered how they felt when they were told that their child had a disability. It became obvious that this news made an enormous impact on parents for them to clearly remember in some cases as far back as 32 years.

The initial phase of the data analysis focused on listing the emotions identified by parents as occurring at the time of diagnosis and throughout the life cycle of the family. The emotions identified as occurring at the time of diagnosis were often the same emotions expressed with different words. After analysis, the many emotions were collapsed into twelve major areas: disappointment, sadness or depression, loneliness, fear, anger, frustration, shock, devastation, numbness, unsureness, and feeling trapped and sorry for the child.

A comparison was then made to identify similarities and differences between fathers and mothers. There were similarities in the emotions experienced by the mothers (N=7) and fathers (N=3) following the diagnosis of their child. Both expressed feelings of fear (M-86%; F-66%),anger (M-57%; F-33%), shock (M-29%; F-33%), feeling alone (M-29%; F-33%) and disappointment (M-14%; F-33%). In addition, fathers expressed feeling sorry for their child and being unsure. Mothers reported feeling confused, sad or depressed, frustrated, devastated and numb. While the range of emotions experienced is similar, the sample is too small to draw any further conclusions.

Mothers and fathers reported having these or similar emotions reoccur intermittently during the life span of their child. None of the emotions were experienced in a prescribed order and often parents reported experiencing more than one emotion at a time. When grieving was not occurring, parents reported being free of these intense emotions. One mother said, "Sometimes I feel so sad and confused about her development, but then she learns to do some new things and all of a sudden I feel like a normal mother for a few days." This contradicts Olshansky (1962) as he indicated that chronic sorrow "continues as long as the defective child lives" (p. 21). Olshansky does not suggest that the emotions ever disappear, rather he points out that the sorrow is always there varying in intensity and duration. In this study, parents reported times when the feelings of grief disappeared for short and sometimes long periods of time. Parents also reported a wide variety of events which triggered the reoccurrence of these feelings which support the work of Cameron et al. (1992).

Events Triggering Reoccurring Emotions.

Parents reported a variety of events which caused the feelings of grieving to reoccur. Each transcript was content analyzed by this researcher and the research assistant to identify commonly occurring themes and patterns among the events that triggered grieving. A modified form of the procedures employed by Odom and Shuster (1986) was utilized. This researcher and assistant independently read the responses to Question 6: *Think about the first five years with your child. Were there any times that some of these intense feelings came back?* They independently listed events that emerged from responses to the question. They then discussed the themes and events negotiating inconsistencies. Theme generation was then conducted for Questions 7-9 (elementary years - post high school).

Keeping in mind that the primary data of in-depth interviews are quotations (Patton, 1987), the following is a representative sampling of events which occurred during the 5 time-spans utilized in the interviews.

<u>During the first five years</u>, a mother whose baby was blind at birth told about her sister having a baby shortly after. "I was happy for my sister but angry that my child was blind."

<u>During the elementary years,</u> for one mother, a reoccurrence occurred at a brother's wedding. Her child who had cerebral palsy and difficulty communicating began acting out. "We just couldn't calm him down and had to

take him home." She expressed frustration, anger at everyone and felt very, very alone.

During adolescence, a father described how happy and proud he was that his adolescent son with Down syndrome was able to work around the house and help with their animals. But he didn't tell anyone because, "I'm sure other people wouldn't see it that way so that made me sad and feel alone."

During the high school years, one mother explained how she felt when she was told about her cousin dating, and her nephew learning to drive. "I liked to do that stuff myself and it made me depressed that she would never do it. That she didn't even know that there was more to do...it was sad to see her just sit."

The post high school years were difficult for one father as he was now retiring. "I was angry at the thought that my work would never really be done...had to ask my oldest boy to take over if the wife and I died."

The intent of this study was to identify events that trigger grieving to reoccur. Earlier studies identified "crisis periods" which caused the emotions of grief to reemerge (McKeith, 1974; Wikler et al., 1981). During the analysis of the data, it became apparent that the events which triggered grieving were numerous and unique to each parent. This means an event may trigger grieving for one parent and not the other.

One mother reported that grieving occurred for her when all the neighborhood children were invited to a birthday party except her child with cerebral palsy. "I was so angry at everyone in the neighborhood and felt so sad for my son. And, I was angry with my husband because he said, 'What did you expect?' I felt like he didn't even care." The event of the neighborhood birthday party triggered grieving for this mother, but not for the father who really did care about his son. Another mom explained, "The grieving process is not a one time event. We, as parents, grieve over and over again as our children's milestones are missed" (Leff & Walizer, 1992, p. 124). The events are unique to each individual and should not be anticipated or judged by others. The cycle of grieving is also unique and may occur frequently or, for some parents, hardly at all.

It's important to note that significant events (e.g. placing child in residential treatment) as well as seemingly insignificant events (e.g. seeing a child at the grocery store the same age as your child and developing typically) were reported as triggers for grieving. These seemingly insignificant events are

significant to some parents based on their perception of the event. Analysis of the many events was conducted. Eight general themes emerged and are listed below with representative quotations.

Health or behavioral issues. "At two years, my child was always sick - upper respiratory problems. Spent a lot of money on medication - confused, angry, and frustrated."

"His older brother died and he was 'out of control' - I had all I could deal with and then he was 'out of control'. I got so frustrated ...and I was in pain too."

Developmental milestones or age appropriate expectations. At one year she rolled on her own and I was so proud of her [I] pulled out her baby book and cried most of the night. Who would ever read the book anyway."

Family issues and relationships. "They [brothers and sisters] sure teased my sister about 'time for another baby' but they never said a word to me. Ya' know that hurt too. Like, maybe I couldn't do it right. My brother even asked if they could have our baby crib and stuff. I felt so down and alone."

Aged parents and retirement concerns. "I still don't have the freedom that I had planned on when I thought about getting close to retirement. I feel tired, and frustrated that my son can't have on-going employment. I don't know how much fight is left in me."

Unusual caretaking demands. "[At] about 17 years our older boys were gone to college and the burden of driving him everywhere was on us again. Very hard, alone and depressed."

Professional and programmatic issues (i.e. school, medical). "The change was difficult. It was like I had to tell her story all over again to the staff at the school. That was frustrating and made you so angry."

Society's lack of understanding and sensitivity. "She was seven and I had to tell the other children [neighborhood]. I was afraid and angry at their questions and very sad when they began to talk about her as different and retarded."

Seemingly "insignificant" events. "Her brother gave her a *MAD of the USA* for her birthday and he was so proud. But it was way beyond her and I cried and cried all over again. I felt so down and sad about it all and angry too that he still didn't get it. She couldn't do what he could."

It is very difficult if not impossible to predict which life events or developmental changes will act as catalysts to grieving. The reoccurrence is unique to each parent and is influenced by his or her perception of the events.

Similarities and Differences Between Mothers and Fathers

A limited number of fathers (N=3) were willing to participate in this study which made it impossible to determine similarities and differences with any validity. However, the fathers who participated indicated they had experienced cyclical grieving. The three fathers identified many of the same emotions as the mothers. Fathers and mothers also identified many of the same type of events as triggering grieving (e.g. developmental milestones, programmatic issues). In a few instances the events mentioned by fathers were not identified by mothers. For example, one father indicated that he experienced a strong reoccurrence of emotions when it came time to register his son for the selective service. From this limited sample, it appears that mothers and fathers may have some events which trigger grieving that differ from each other, however, more research needs to be done because of the small sample. Fathers hurt as deeply as mothers but often do not show it publicly (May, 1991). This may account for the unwillingness of fathers to be interviewed.

The findings from this study support the premise that both seemingly significant and insignificant events can cause grieving to occur. Parents interviewed described both types of events as triggers. How the parent perceives the event appears to be the catalyst. The findings of this study clearly support the concept of cyclical grieving.

Limitations and Future Study

The subjects for this study were not randomly sampled; they were parents who volunteered to be interviewed. The intention of this study was to interview parents of older children (i.e. young adults) with disabilities who would have experienced a substantial portion of their children's lives. This would make it possible for parents to determine if grieving occurred in cycles. However, because of the long time span (21 to 39 years) it was difficult for some parents to recall events. Focusing the interview into five time-spans was an effective strategy for assisting parent recall. Another limitation is the types of services children and families received 20 to 40 years ago.

In future research, it would be helpful to do a longitudinal study, interviewing parents periodically throughout the life span of their child which would promote accurate recall. Future research also needs to investigate how the concept of Cyclical Grieving relates to parents outside the mainstream culture as well as the patterns of grief for grandparents and siblings. Another question

about cyclical grieving might involve support systems as a factor when looking at parents who seemed to handle the process well compared to those who had additional problems.

Presentations to Parent Groups

To further validate the accuracy of the concept of Cyclical Grieving, this researcher presented the concept to six parent groups which included 118 parents (approximately 33% fathers; 66% mothers) of children with disabilities birth to 22 years. The children had a wide variety of disabilities ranging from mild to severe. The parents were primarily Caucasian and represented both rural and urban areas with low to middle socioeconomic status. This researcher presented Cyclical Grieving using a lecture format, transparencies and handouts. Open discussion with questions and answers was held following each presentation. At the conclusion of each presentation, parents were asked to react to the concept of cyclical grieving indicating if it did or did not accurately represent their emotional experiences as they reared their child with the disability. This was done through open discussion with the smaller parent groups (15 - 20) and by responding to a question on the program evaluation with the larger groups. In the discussion groups and on the evaluations that were turned in, parents unanimously supported the model as an accurate representation of their emotional experiences. Many parents told stories about events describing the cyclical nature of their grieving. The parents' stories supported the fact that significant and seemingly insignificant events trigger grieving. They also reinforced the notion that the frequency and intensity of grieving cycles are unique to each parent. In addition, a number of parents commented that finally someone understood what they were going through. The data from the parent groups support the findings of this study. The process of having 118 parents react to this concept provides a cross-check (Fetterman, 1989) to the findings of this exploratory study and increases the validity of the concept of Cyclical Grieving as an accurate representation of parents' emotional experiences.

Implications for Professionals

The findings from this study have implications for working with families, for personnel training and future research. In order to be successful when working with families who have children with disabilities, understanding comes first. Knowledge about Cyclical Grieving will help professionals more fully understand what parents experience as they raise their child with a disability being aware of

feelings that reoccur throughout the life cycle of the family. This reoccurrence has implications for on-going support systems which recognize the changing needs of the family. Information about the cyclical grieving process should be a part of every preservice program for professionals. Inservice training on these issues should be provided for professionals already in the field. As stated earlier, future research needs to focus on cultures outside the mainstream and their emotional reactions as well as the grieving process experienced by grandparents and siblings.

It is important to remember that while parents report experiencing cyclical grieving, they also report positive experiences with their children and stress their deep love and concern for them. Professionals need the knowledge to understand parents and the skills to help them refocus from their shattered dream and begin dreaming new dreams while remaining positive and hopeful.

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Cyclical Grieving Model

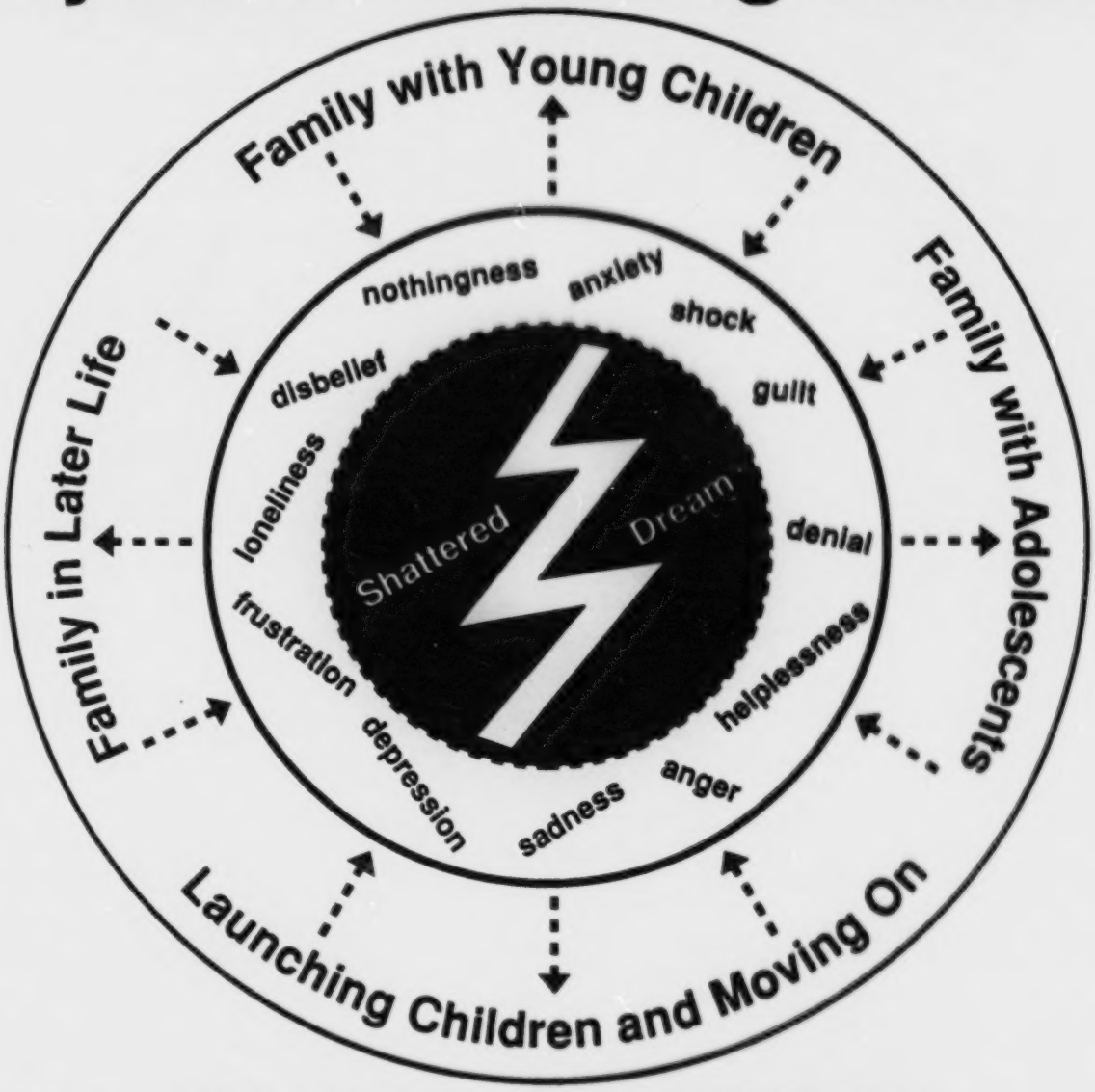

Figure 1 **Inner Circle- Shattered Dream**
Middle Circle- Reocurring Emotions
Outer Circle- Intermittent Grieving Throughout Life Cycle of Family (Blaska, 1993)